



The Edmond J. Safra Fellowship in Movement Disorders

*Bridging the Gap in Parkinson's
Research and Care*



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

“The Edmond J. Safra Fellowship in Movement Disorders provides a unique sense of energy and commitment that comes from being part of something greater than ourselves — a collective desire by everyone involved to alleviate the suffering of those living with Parkinson’s now, with the hope of a future in which the disease will be a thing of the past. It’s a community with a common cause.”

— Irene H. Richard, MD

Fellowship Director, University of Rochester

The Right Doctors Make a World of Difference

A Note from Dr. Rachel Dolhun



For anyone living with disease, seeing the right doctor can make a world of difference. The “right” doctor is different for everyone — for some, good listening skills are the most important quality; others want the leading researcher in the field. No matter what specific characteristics a person living with Parkinson’s looks for in their physician, a movement disorder specialist often is the “right” type of doctor. Because these experts have additional training in diagnosing and treating Parkinson’s, they help people and families navigate all facets of life with the disease, from diagnosis through later stages of the Parkinson’s journey. Movement disorder specialists can adjust complex treatment regimens, manage new and evolving symptoms as disease unfolds, and engage patients in the latest research.

But not everyone with Parkinson’s receives expert care because there aren’t enough movement disorder specialists. To meet this need, The Edmond J. Safra Fellowship in Movement Disorders — a collaboration between the Edmond J. Safra Foundation and The Michael J. Fox Foundation — annually funds five international academic centers to each train a new specialist over two years.

Since its 2014 launch, The Edmond J. Safra Fellowship in Movement Disorders has granted funding to 18 distinguished institutions spanning 10 states and

five countries. By the year 2022, these programs will graduate 26 new movement disorder clinician-researchers who will deliver high-quality care for patients with Parkinson’s and other movement disorders and advance research breakthroughs to better understand and treat these conditions. This growing global network will have far-reaching and lasting impact on people with Parkinson’s and the field of movement disorders.

With deep gratitude for the support of the Edmond J. Safra Foundation and immense pride, we present our second graduating class. The five accomplished movement disorder specialists in the Class of 2019 are advancing to the next step in their careers, where they will build on the knowledge and experience they have gained during the fellowship to provide expert care and lead research directly informed by their patients’ most pressing needs. We applaud their passion and dedication, and wish them continued success helping people with Parkinson’s both at the bedside and in the lab.

Looking forward,

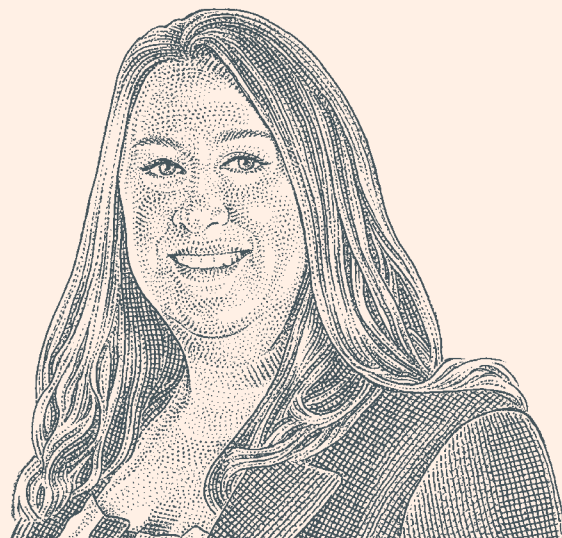
Rachel Dolhun, MD
Vice President, Medical Communications

Class of 2019 Fellows

Katie Amodeo, MD

University of Rochester
Rochester, New York

Being Part of the Solution



Having had an early encounter with neurodegenerative dementia — my great-grandmother had Alzheimer's dementia — I knew I wanted to be a part of the solution to dementia in neurodegenerative diseases. During my early training in medical school and residency training in neurology, I was drawn to Parkinson's disease (PD) and other parkinsonian disorders, leading to my pursuit of a career in movement disorders with a focus on cognition.

Giving Dementia Patients a Chance to Participate

One issue I investigated during my fellowship was the potential link between cognitive symptoms and orthostatic hypotension — when patients have a shift in blood pressure and become lightheaded when they stand up or make other postural changes. At the University of Rochester, I began a pilot project with patients living with Parkinson's disease dementia or dementia with Lewy bodies. With a lot of clinical trials, these patients are excluded because they are in a later stage of disease. Most were so excited to be able to be a part of something and to potentially help others with this disease.

I have also taken the reins of the duopa program at the University of Rochester. Duopa (a gel form of levodopa that's administered continuously through the intestine) is a therapeutic option for those with advanced motor fluctuations in PD. This treatment can be very beneficial in restoring motor

function. Hearing the joy from one patient about being able to work in her garden again was very rewarding.

Caring for the Caregivers

Having had early experiences with dementia in my great-grandmother, I'm also mindful of the toll that caring for someone with PD-related dementia can take on family members. I have launched and continue to run a support group for care partners of those with Lewy body dementia (including PD with dementia and dementia with Lewy bodies). It's a tremendously gratifying experience. I bring in speakers, but mostly, everyone just talks. It is amazing how much they learn from each other — and how much I learn from them. The goal is to see care partners feeling supported and equipped with the tools they need. I'm grateful to be part of that.

After completing my fellowship at the University of Rochester Medical School, I am staying on as an assistant professor in neurology, with a secondary appointment in psychiatry.

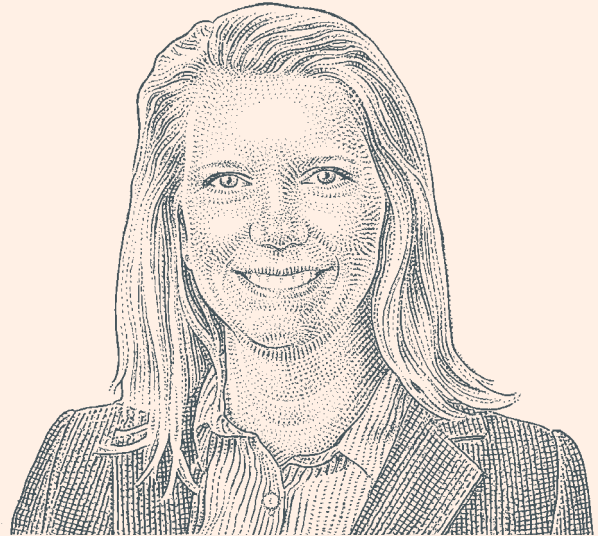
As told to Paula Derrow

Illustrations by Nancy Januzzi

Sarah Horn, MD

University of Pennsylvania
Philadelphia, Pennsylvania

A Reason for Optimism



From the time I was a teenager, I was aware of what having a movement disorder could do to an individual and their family. I had a great-aunt who died of multiple system atrophy, a disease that's related to Parkinson's.

A Thought-Provoking Puzzle

In many areas of medicine, you make a diagnosis with a blood test or a scan, but with Parkinson's disease (PD), you listen to a patient's symptoms and do a clinical exam. It's a thought-provoking puzzle, which I find satisfying. You look at the tremor, feel muscle tone, and check for weakness or numbness. It's about the art of examination. This "hands-on" doctor-patient relationship is part of what drew me to the field of movement disorders.

The chance to get involved with research as part of my fellowship was an unexpected highlight. Among other things, I looked at two different medications used for treating PD psychosis, a symptom that affects roughly half of patients, and compared outcomes. I also saw first-hand how important it is to have specialized knowledge about the nuances of these and other PD treatments. (That's one of the things I got from

the fellowship.) I had a Parkinson's patient who had been hospitalized with confusion and hallucinations. But I tweaked his medications, his cognition cleared up, and he is now living at home and able to socialize.

Sharing a Positive Outlook

I'm taking my specialized knowledge to the University of Texas Medical School in San Antonio as an assistant professor of neurology. I plan to provide clinical care, with a focus on PD, for movement disorder patients, as well as teach medical students, residents and patients' family members.

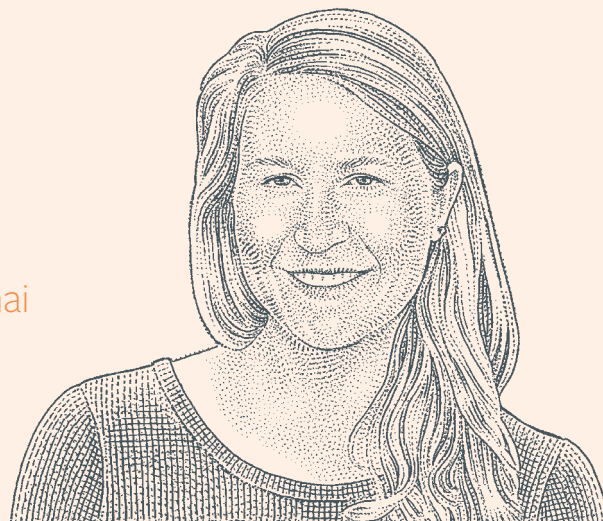
Patients and families have reason to be positive. There is so much research going on that I know we will make leaps and bounds of progress. My hope is that during my career, we will find a therapy that will slow down the progression of Parkinson's disease. I'm optimistic.

Class of 2019 Fellows

Katherine Leaver, MD

Icahn School of Medicine at Mount Sinai
New York, New York

On the Cusp of Something Big



When I was a resident in movement disorders rotating through various clinics, I was captivated by the endless variety I saw in the patients with Parkinson's disease (PD). The disease affects so many systems of the body that, in a way, you have to develop expertise in *everything*. It never gets boring. You can see 10 patients and each one will be different from the next. Really, it's individualized medicine.

Becoming a True Expert

With PD, it's not always like what you read in a textbook. The need to approach every patient individually is one reason why the fellowship has been so crucial to my training. I've been exposed to so many patients that I've really been able to appreciate the scope of the disease, and to become a true expert. And I've learned that it's important to be a good listener because it can lead to a more perceptive diagnosis. If you keep the conversation short — *Why are you here? Boom, boom, boom!* — you can miss things. If you let people talk through what's going on, you sometimes realize that there may be deeper medical issues than what they're presenting you with.

Exploring the Genetic Link to PD

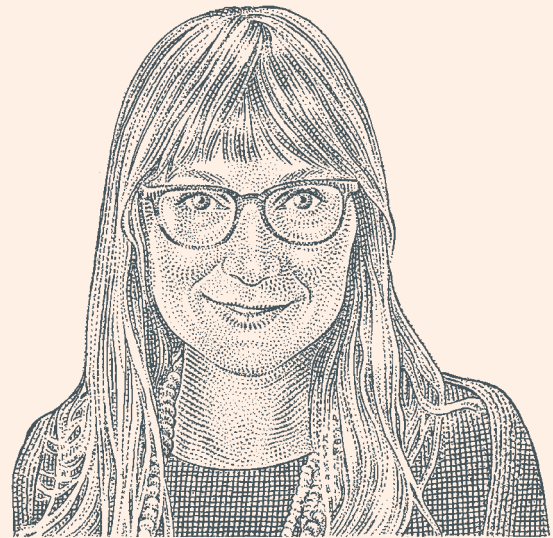
My research includes examining how Parkinson's patients with a LRRK2 mutation respond to deep brain stimulation. The better we understand patients who have this genetic mutation, the greater the chances that we can extend our observations to patients who don't, so we can work on developing more effective disease-modifying treatments.

I'll be staying on as a faculty member in the division of movement disorders at Mount Sinai Beth Israel. And my ultimate goal is to develop more targeted therapies for PD. My hope is that we'll be able to meet patients and use the information from their genetic testing to inform the choice of treatment. It feels like we're on the cusp of something big.

Jessica Weinstein, MD

University of California, San Francisco
San Francisco, California

A Passion for Patients



I was not the typical pre-med student in college. It was my interest in philosophy, as much as neuroscience, that led me to the field of movement disorders and Parkinson's disease (PD). I've always been drawn to the question of what makes us human. As a pre-medical student, I worked with patients with different types of dementia and atypical parkinsonism. These conditions affected their personality and their movement — both of which are primal to what makes us human.

A Specialty with a Touch of Sci-Fi

Observing the perseverance of patients and the ability of the brain to adapt has always inspired me. I cared for a patient who had lost his ability to speak, but even though he had no language, his musical ability continued to flourish. Even when we don't have a cure for someone's disease, I like to see silver linings, and the way other parts of the personality can develop and expand.

During my fellowship year, I researched the non-motor side effects that can occur with deep brain stimulation (DBS). What I love is the fact that there are different treatments to offer patients. Whether it's "sci-fi" treatments like DBS or levodopa, I can often make a significant impact.

A Focus on Patients in Need

I am passionate about providing excellent neurologic care to underserved populations. After one year of fellowship, I accepted a position with Kaiser Permanente in California and am working as the only trained movement disorder expert in a relatively rural and underserved area. It's thrilling to me to be able to provide this level of care, whether through DBS or Botox administration. I can see how excited patients are to be able to have access to these treatments so close to their homes.

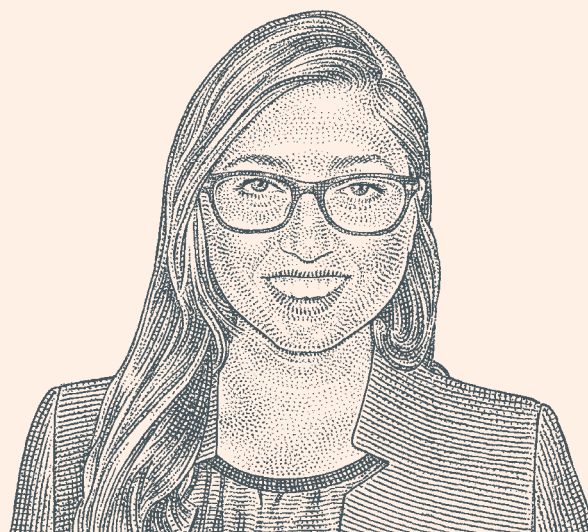
The long-term relationships I form with patients are so meaningful. Whether we're talking about sleeping issues or ways of dealing with depression and anxiety, I appreciate their openness and self-reflection. I'm treating the whole patient, getting to know the individual over time. That's indispensable to my job.

Class of 2019 Fellows

Natalie Witek, MD

Rush University
Chicago, Illinois

Keeping Patients on the Move



When my father had an intracranial hemorrhage, my greatest wish was to see him get up and walk out of the hospital. Unfortunately, that wasn't the reality for him. But I became drawn to the movement disorders field because you *do* have the ability to offer patients amazing treatment options. You can help them to get up, walk, move, dance and do the things they love to do. I wanted to be part of that journey.

Mobilized and Motivated

The patients I saw during my fellowship were some of the most mobilized people I've ever met. They understood that there's always more to be done, whether it's exercise, physical therapy or deep brain stimulation. And the therapeutic options in the pipeline are very promising.

I've been spurred on by experiences with patients and their families, including a woman who went from not being able to walk, speak or feed herself to, after treatment, regaining the ability to live her life again.

To see the patience of this woman and her family, to have their trust, was very humbling and moving.

Making Connections

But treatments and trials aren't the only things that matter. And just because symptoms are mild doesn't mean patients aren't impacted. I appreciate the chance to bolster patients emotionally. While having Parkinson's can slow you down, patients are learning that we can help them continue to live healthy, happy and successful lives.

After fellowship, I'm staying on at Rush as an assistant professor in the department of neurology, section of movement disorders. I'm particularly interested in studying immune markers in patients with Parkinson's disease. The goal is to see if we can find a biomarker that would help identify patients who might respond better to therapies that alter the immune system. We know that no two patients with Parkinson's disease are the same, and I hope to identify individual markers that may successfully alter the underlying disease process.

Class of 2019 Fellowship Directors

Susan Bressman, MD

Icahn School of Medicine
at Mount Sinai
New York, New York

Susan Bressman is the Mirken Family professor of neurology at the Icahn School of Medicine and a director of the Movement Disorders Center for the Mount Sinai Health System. Her clinical research focuses on identifying diagnostic and progression markers and disease pathways for Parkinson's disease (PD); she is the site principle investigator for The Michael J. Fox Foundation's (MJFF) Parkinson's Progression Markers Initiative study. Susan also works on gene identification for Parkinson's, dystonia, tremor and other movement disorders. She has served on scientific advisory boards and committees of the National Institutes of Health, MJFF, The Bachmann-Strauss Dystonia and Parkinson Foundation and others.

Nabila Dahodwala, MD, MS

University of Pennsylvania
Philadelphia, Pennsylvania

Nabila Dahodwala is associate professor of neurology at the University of Pennsylvania. Her clinical interests include Parkinson's disease and other movement disorders and her research interests involve access to care; disease prevention and health promotion; disparities and health equity; and global health and risk communication. Nabila leads a number of projects that study patient, physician and health system-level barriers to high-quality care for individuals with neurodegenerative diseases. She is the site principle investigator for MJFF's Parkinson's Progression Markers Initiative study and a member of MJFF's Fox Insight Executive Steering Committee. Nabila also participated in MJFF's Technical Advisory Group to study the economic burden of Parkinson's disease.

Nicholas Galifianakis, MD, MPH

University of California,
San Francisco
San Francisco, California

Nicholas Galifianakis is associate professor of neurology at the University of California, San Francisco. As a neurologist specializing in Parkinson's disease, essential tremor, dystonia and other movement disorders, his research interests include outcomes in deep brain stimulation, the development and implementation of innovative models of care for PD, and using telemedicine to facilitate clinical trial participation. In a study of PD and dementia, he and his colleagues utilized Fox Trial Finder, a resource created by MJFF, to recruit participants. Nicholas is a member of the American Academy of Neurology and International Parkinson and Movement Disorder Society.

Class of 2019

Fellowship Directors

Katie Kompoliti, MD

Rush University
Chicago, Illinois

Katie Kompoliti is professor of neurology, educational director of the section of movement disorders and director of the Movement Disorders Fellowship Program at Rush University Medical Center. She is the author and co-author of numerous publications in prestigious journals. Her clinical interests as a principal investigator have focused on several therapeutic areas including studies to evaluate the safety and efficacy of new compounds to treat Parkinson's disease, Tourette's syndrome, functional movement disorders and dystonia.

Irene H. Richard, MD

University of Rochester
Rochester, New York

Irene H. Richard is professor of neurology and psychiatry and director of the Movement Disorders Fellowship Program at the University of Rochester. She provides neurological care for patients with Parkinson's disease and related conditions, and conducts clinical research aimed at understanding and developing treatments for these conditions. She is a principal investigator (PI) for an MJFF-supported study of buspirone for anxiety in PD and site PI for several multi-center clinical studies, including MJFF's Parkinson's Progression Markers Initiative. Her efforts over the years have brought new clinical and research attention to mood and anxiety disturbances in PD. Irene has authored research articles and book chapters and also has served as a reviewer for scientific journals and grant proposals. Irene has also served on the Scientific Advisory Board and as Senior Medical Advisor, and has chaired several research grant review committee meetings for the Foundation.

Rachel Saunders-Pullman, MD, MPH, MS

Icahn School of Medicine
at Mount Sinai
New York, New York

Rachel Saunders-Pullman is Bachmann-Strauss professor and associate professor of neurology at the Icahn School of Medicine at Mount Sinai, and chief of movement disorders at Mount Sinai Beth Israel. Her clinical research focuses on the study of genetic and epidemiologic factors relating to Parkinson's disease and dystonia. In particular, she is evaluating the relationships between genetic status and disease onset and progression, especially for carriers of LRRK2 and GBA mutations. She also is engaged in additional gene identification in both PD and dystonia. She is on the steering committee of the Parkinson's Disease Biomarkers Program (PDBP), and serves on the Scientific Review Committee of the Parkinson's Study Group and the Scientific Program Advisory Committee of the American Neurological Association.

Classes of 2020 and 2021 Fellows

Eleven additional movement disorder specialists are receiving vital training with support from The Edmond J. Safra Fellowship in Movement Disorders.

2020

Juliana Coleman, MD

UAB — University of Alabama at Birmingham
Birmingham, Alabama

Fellowship Director: David Standaert, MD, PhD

Grace Crotty, MBBChB, MRCPI, MD

Massachusetts General Hospital
Boston, Massachusetts

Fellowship Director: Alice Flaherty, MD, PhD

Eric Jackowiak, MD

University of Michigan
Ann Arbor, Michigan

Fellowship Director: Praveen Dayalu, MD

Greg Kuhlman, MD, MBA

Toronto Western Hospital
Ontario, Canada

*Fellowship Directors: Susan Fox, MBChB, MRCP, PhD
and Tony Lang, OC, MD, FRCPC, FAAN, FCAHS, FRSC*

Kimberly Kwei, MD, PhD

Columbia University
New York, New York

Fellowship Director: Oren Levy, MD, PhD

2021

Whitley Aamodt, MD, MPH

University of Pennsylvania
Philadelphia, Pennsylvania

Fellowship Director: Nabila Dahodwala, MD, MS

Amir Badiei, MD, MS

University of California, San Francisco
San Francisco, California

Fellowship Director: Nicholas Galifianakis, MD, MPH

Christopher Caughman, MD

Emory University
Atlanta, Georgia

Fellowship Director: Stewart Factor, DO

Neil Shetty, MD

Northwestern University
Chicago, Illinois

Fellowship Director: Tanya Simuni, MD

Judith van Gaalen, MD

Radboud University
Nijmegen, Netherlands

*Fellowship Directors: Bart van de Warrenburg, MD, PhD,
Bart Post, MD and Prof Bastiaan (Bas) Bloem, MD, PhD*

Anne Weissbach, MD

University of Lübeck
Lübeck, Germany

Fellowship Director: Christine Klein, MD

The Art and Science of Parkinson's Research and Care

Artist Tom Shannon and The Edmond J. Safra Fellowship in Movement Disorders

People with Parkinson's disease (PD) and their loved ones know the importance of finding a good doctor to help them with their Parkinson's journey. When building a care team, a movement disorder specialist, a neurologist with additional training in PD and other movement disorders, provides the knowledge and experience necessary to optimize care, advance research and connect the dots between the two — there's truly an art to what they do.

As a person living with Parkinson's, renowned New York-based artist Tom Shannon has a deep appreciation of the role these individuals play in patient care and research. So when The Michael J. Fox Foundation (MJFF) and the Edmond J. Safra Foundation asked Tom to create a recognition piece marking the important milestone of graduating from The Edmond J. Safra Fellowship in Movement Disorders, he went right to work.

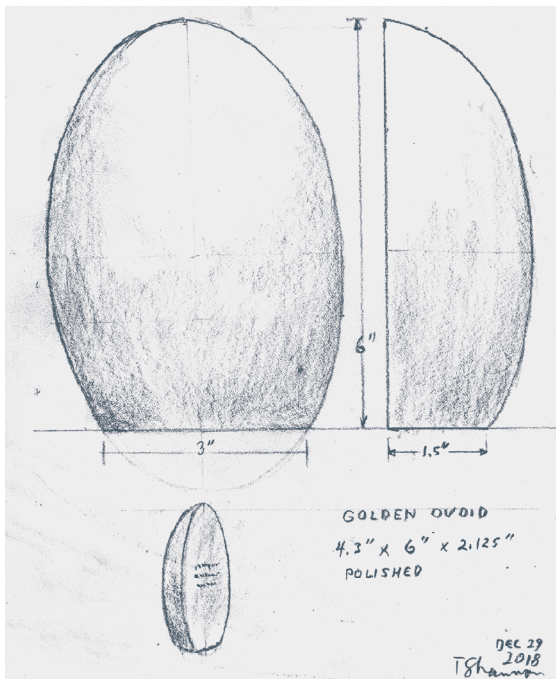
Tom has a passion for creating conceptual sculptures that express the precision and balance of science and art. And his long-standing friendship and connection to MJFF and the PD community made this project incredibly poignant. "I am grateful for the opportunity to contribute what I can to support the morale of those who are doing the difficult work of caring for Parkinson's patients," says Tom.

From Concept to Creation

Tom's work is idea-driven and incorporates scientific themes, and during the initial phases of his creative process, he often poses a question that the piece will hopefully answer. Thinking about this piece and what it represents, he pondered, 'what form might represent a feeling of hope and clear thinking?' Tom elaborates, "I sought to make a simple, unified form that could be enjoyed as a sculpture beyond its function as an award."

During his creative process, he referred to the pieces as a 'golden ovoid,' representative of a "flame lighting the path to the knowledge needed to solve the problem," says Tom, which embodies the spirit of the fellowship program. To tie the question and artistic vision together, he considered materials that have specific characteristics which represent his conceptualization. To convey brightness and precision, he selected polished metal.

The final piece of art not only celebrates the contributions to the patient, medical and research communities, but also serves as a reminder that the fellowship places an emphasis on balancing research and patient care. When people interact and view the piece on display, Tom hopes they experience a pure, beautiful form that conveys a sense of unity.



clockwise from top:

The final, engraved recognition piece for David Breen, 2018 graduate of The Edmond J. Safra Fellowship in Movement Disorders.

Artist Tom Shannon sits among his artwork in his New York City studio.

Pencil sketch of the 'golden ovoid' which became the recognition piece for graduates of The Edmond J. Safra Fellowship in Movement Disorders.

Class of 2022

Fellowship Centers

The Michael J. Fox Foundation is proud to announce the academic centers that will host the fifth class of The Edmond J. Safra Fellowship in Movement Disorders.

Baylor College of Medicine

Houston, Texas

Toronto Western Hospital

Ontario, Canada

UAB — University of Alabama at Birmingham

Birmingham, Alabama

UCL Queen Square Institute of Neurology

London, England

University of Florida

Gainesville, Florida



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

As the world's largest nonprofit funder of Parkinson's research, The Michael J. Fox Foundation is dedicated to accelerating a cure for Parkinson's disease and improved therapies for those living with the condition today. Funding more than \$850 million in research to date, the Foundation pursues its goals through high-impact research efforts coupled with an active global engagement of scientists, Parkinson's patients, business leaders, clinical trial participants, donors and volunteers.

www.michaeljfox.org







EDMOND J. SAFRA
PHILANTHROPIC FOUNDATION

Edmond J. Safra, one of the 20th century's most accomplished bankers and a devoted philanthropist, established a major philanthropic foundation to ensure that individuals and organizations would continue to receive his assistance and encouragement for many years to come. Under the chairmanship of his beloved wife Lily, the Edmond J. Safra Foundation draws continuing inspiration from its founder's life and values, and supports hundreds of organizations in more than 40 countries around the world. Its work encompasses four areas: Education; Science and Medicine; Religion; and Humanitarian Assistance, Culture and Social Welfare. The Foundation has provided significant funding for Parkinson's disease research and patient care at dozens of hospitals and institutes in places as varied as Natal (Brazil), Toronto, New York, Grenoble, Paris, London and Jerusalem.

www.edmondjsafra.org

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